A National Web Conference on Effective Design and Use of Patient Portals and Their Impact on Patient-Centered Care

Questions and Answers

March 23, 2017

QUESTION:

How do physicians feel about patient portals? For example, how do they feel about patient messaging? Are they allowed to bill for their time responding to questions? How do patient portals benefit physicians?

ANSWERS:

Courtney Lyles:

The systems that have figured out messaging the best have been the integrated delivery systems. These systems are capitated for the payment of their patient population, meaning that one provider is responsible for an entire panel of patients. Providers are salaried, and it makes most sense to communicate with their patients through any format to help them stay healthy, stay out of the hospital, and prevent complications.

It gets more challenging in a fee-for-service environment. Our system is mixed in that setting. We did a little provider surveying, and that is one major concern, that of protected time to do this. I know anecdotally that businesses like Kaiser give some protected time for emailing, but the volume of emails just keeps going up, so it's an ongoing challenge that we need to study.

Ruth Masterson Creber:

In our acute care portal, patients are able to submit questions to providers, but it isn't a two-way messaging system. Even though functionality is present in the portal, very few patients utilize it, and we're not exactly sure why. Some older adults were primarily receiving care in these units, and that may not be the way they are typically expected to interface with their providers. When patients did ask questions, providers would address those the next time they went into the room.

Jessica Ancker:

To deal with this, the outpatient setting that I was working in—the federally qualified health center—created a triage approach for patients. They set a very firm expectation that every patient should get a response within 24 hours, which they're amazingly good at doing. They have a triage approach: First the emails are screened. Then they go to the front desk, scheduling, medical assistants, nurses, or doctors for answers. Anecdotally, I would agree with what Courtney said—that the volume of messaging is going up. It's not explicitly reimbursed for, and I think that's a problem. The health center is a salaried organization too, so there's no feefor-service incentive on the part of the individual doctors. But it's still limited time.

QUESTION:

What's a key strategy that can get more patient engagement in your portal?

ANSWERS:

Ruth Masterson Creber:

One of the important things is having support from providers. Providers should ask patients if they're using the portal and express interest in patient engagement in their medical and clinical information. This helps patients get excited about the portal.

It's also important to have a specified person who supports the patient, especially with the initial navigation of the portal. We have a research assistant who does this.

Jessica Ancker:

The health care system is not optimized for the realities patients face, such as language barriers, time, convenience, and health literacy. We need to think about how we can meet the patient's needs, rather than offering a product that only certain patients are able to use. Using training videos is a great idea. We did a little work with training sessions, but we're not able to scale that up due to the amount of time and resources it would take.

Ruth Masterson Creber:

I agree that provider and staff engagement and referral and recommendation are critical pieces. It has been shown in some of our previous work at Group Health how important that is for patients themselves being a user. There are going to be a lot of patient questions, and there's just not sufficient time in a visit to address all those questions. So it's important to have a strategy for managing those questions, even if you can't make a full-blown training program right off the bat. Make sure the uptake is diverse—not just the most engaged or healthy patients who might be the most likely to sign up first.

QUESTION:

Which EHR vendor did you use for the acute care patient portal? Or did you develop that application in house?

ANSWER:

Ruth Masterson Creber:

We developed the application in house.

QUESTION:

Did the clinician notes in your portal have hyperlinks for definitions of the medical terms?

ANSWER:

Ruth Masterson Creber:

Patients wanted to have access to clinician notes, but they didn't understand them. We are working on a program that would help explain some of the acronyms and words that are harder for patients to understand.

QUESTION:

What strategies did you use for patient tablets and infection control?

ANSWER:

Ruth Masterson Creber:

Patients typically had the tablet for the duration of their admission. Between patients, we wiped down all the tablets with antiseptic wipes.

QUESTION:

Were there differences between Spanish and English users? Did you capture literacy and educational demographics in your project?

ANSWER:

Ruth Masterson Creber:

We have very detailed demographic information on all the patients, as well as information about their technological and health literacy. When we publish the results of the study, we will be looking at any differences. The important thing is that the portal is accessible to both English and Spanish speakers. Our research assistants are all bilingual. The study is explained in both Spanish and English, and the questionnaires are in both languages.

QUESTION:

Did you get much resistance from providers?

ANSWER:

Ruth Masterson Creber:

Prior to implementing the study, we did a clinician survey with 53 clinicians in the hospital where this was implemented. We found that most of the providers agreed or strongly agreed with giving patients access to most aspects of a patient's data in the portal. There was a subgroup of providers who strongly disagreed with giving patients access to consultation notes, progress notes, and procedure reports. Currently, only patients who are enrolled in this subgroup of the study have access to the clinical notes.

QUESTION:

Will patient review improve the accuracy and completeness of medical records? What do you think about patient correction for interpretations of what's presented in a portal?

ANSWERS:

Jessica Ancker:

Everything that I've presented is secondary analysis of EHR data. That has advantages and disadvantages; I can see the data but I don't necessarily know why I am seeing what I am seeing.

We did look at the problem list, and whether it was being regularly updated by the provider. We thought that might be a proxy for the provider's documentation completeness or how they were using the EHR. We thought the provider might be more likely to keep the problem list up to date for patients who were using the portal because the patients should be looking in there and potentially catching omissions or commissions. We did not see evidence of that.

Courtney Lyles:

I don't have any specific data about that. But I think it's an underlying assumption that the more patients have access to information, the more information will be correct. Even medication lists from the after-visit summary that are available in the portal often have mistakes. There isn't always enough time to do medication reconciliation in the outpatient space. There are many things to double-check and go over. I see the portal as not just for correcting information, but also as an engagement tool; the more patients are looking at information, the more aware they are.

QUESTION:

Are you planning to look at whether the uptake in the patient portal changes clinical outcomes?

ANSWER:

Jessica Ancker:

Yes, I am. I'm currently supported by a career development award from AHRQ. When I applied for the grant, few people had done any outcome-type work. I proposed that I would spend 2017 to 2018 doing that study. In the several years since I submitted the grant, a lot of people have started publishing that type of work—showing that under certain circumstances and with certain types of patients you can link portal use to better outcomes. Some of the messaging work, particularly coming out of Kaiser, has demonstrated beneficial outcomes.

As a result, I've adjusted my plan slightly. Currently, I'm right in the middle of EHR data collection for a study looking at patient upload function. We're allowing diabetic patients to upload their own blood glucose and patients who have hypertension to upload their own blood pressure. A relatively small cadre of people are regularly uploading their data to their physician in advance of their next medical appointment. We suspect this process will help them communicate with their physician and manage their own health, but no one has demonstrated that yet.

QUESTION:

Do your patients need to have an email account to opt out?

ANSWER:

Jessica Ancker:

Patients need an email account to set up a portal account (a number of people got help setting up a Gmail account in order to do that), but they do not need it to opt out of portal use. Instead, if the patient says they do not want the portal, that is recorded in the record and they are not asked again.

As part of the registration or activation process, an email message is sent to your Gmail account. You need to click through and validate your identity in order to access it. We found a substantial minority of patients ended up using the portal on their phone anyway.

QUESTION:

Do you have any data on how much time patients spend reading information?

ANSWER:

Jessica Ancker:

No, we don't. If a patient clicks on the info button, a MedlinePlus pop-up window opens. We don't know how long they spend reading the MedlinePlus information, or if they read it at all.

QUESTION:

How did you implement the training?

ANSWERS:

Courtney Lyles:

We enrolled patients. The patients then came in and filled out a consent form (because it's a research study). In some cases, they watched videos with us, and we answered their questions about the portal. In other cases, we gave them a brochure about the portal and sent them home with the printed link and a few key screenshots about how to access the how-to video.

We were interested in how to scale this more broadly because in-person training is a very time and resource intensive task. We were trying to get at how much better we could do in person

versus just providing more training materials on a static Web site. That's what we'll be evaluating in the 6 months following training that we're now completing the data collection on.

Patients need an email account to sign up for our portal as well because we felt like that was the right group of patients to start with—patients with a certain amount of digital literacy. Probably a third of the patients in our study hadn't signed in to their email account for 6 to 9 months and needed us to help them reset their password. It's a challenge these days; many people are not using email as much as they used to—especially among our sample of an underserved patient population.

QUESTION:

Doctors use different types of portals. If a patient is seeing multiple doctors, there might be a challenge with respect to portal access and being able to effectively use a portal. Have you encountered that?

ANSWERS:

Jessica Ancker:

Yes. I did encounter that. We did an in-depth interview study with patients—primarily here at Cornell. We didn't select only portal users; we recruited more broadly from the primary care clinic. We found that when you recruited that way, you found relatively few people who were using the portal. The ones who did were relatively savvy. One guy who was a veteran had some of the information at the VA account, and he knew that he had to export this report and bring it to his physician here, because he knew that they didn't communicate.

We recently published a paper in the *Journal of Medical Internet Research* about the burdens that patients face—especially patients with multiple chronic conditions who see doctors in different medical systems. Their information often falls through the cracks; for instance, their lab results may be done at one place and are not delivered to another place on time because of a lack of interoperability. These patients need to carry their own medical information back and forth, and it's really a burden. If you're sick and have a lot of things wrong with you, this is one more thing to worry about.

Courtney Lyles:

I fully agree that it can be a burden. I don't see it as much in our system. Most of our patients are with us for primary, specialty, and hospital care in the same system, so the portal would serve them. But when we go out into the community (such as at libraries and senior centers), we would have to know how to use all the portals that are available in the city and county of San Francisco, and even more broadly, to be able to help people access all of them. That's a real challenge, both on the patient side and for people trying to work with community-based groups on this issue.

QUESTION:

Do you have any thoughts about smartphone apps for portals?

ANSWERS:

Courtney Lyles:

We have thought about it a lot. When Kaiser in Northern California launched their app (kp.org), they got maybe around a 5 to 7 percent bump in total usage, without decreasing the racial and ethnic differences that I showed. That suggests that you might be getting different patients, but you might not. If people are really engaged and want to use the system, they might have already figured out how to do it through a computer version or the mobile browser on their

phone; they're still using it on their phone, but it's not through an app, per se. When we think about it in the safety net, it becomes a more primary means of device ownership for our patient population. Although many of our patients use smartphones, a lot of them don't use many apps.

They use some of the basic functionality on their smartphone. It depends on how old they are and some other characteristics.

So it's important to optimize the portal for mobile device use, which is not often done. It's also important to offer an app version, but don't expect it to be a silver bullet.

Jessica Ancker

We found that too. The Institute for Family Health implemented a mobile version and a mobile app. Compelling data from the Pew Research Foundation and others shows that patients are more likely to access the Internet via their phone than by computer and that many patients progress directly to a smartphone without ever using a computer. When they implemented the mobile app, they found that a small group of people used it. But it was not the kind of overwhelming response that they had hoped for.

Anecdotally, when I've interviewed patients at clinics, I've found that the more educated and affluent patients are the most enthusiastic users of the app. These are the people who are already using their phone for services, such as banking, so they're also happy to use their phone for this purpose.

Using an app is trickier in practice than in theory. We run into iPhone versus Android issues; not everything is adaptable to both. We also run into smartphone version issues; some patients are still using clamshell/flip phones, while others have an iPhone from three versions ago. And a lot of patients don't have a phone of any kind. If we had usable phone apps for every possible phone version, we might be able to reach more people.

QUESTION:

Have you collected patient reported outcomes through your patient portals? If so, which ones?

ANSWERS:

Ruth Masterson Creber:

We haven't collected much in the project that I shared, but my other project is about collecting patient-reported outcomes using a mobile health application. In our patient portal right now, we are not specifically doing that, but we are going to be expanding the acute patient portal to be able to collect more patient-reported outcomes.

Jessica Ancker:

I've just started working with Memorial Sloan Kettering Cancer Center on a patient-reported outcomes system for ambulatory cancer surgery to help patients self-report side effects and recovery from surgery. To date, they seem to have a small and relatively enthusiastic group of users. But we're just starting, so I don't have much data.

Additional Q&A Addressed Following the Webinar

QUESTION:

Ruth reported that participants tended to **not** use the informational links very much, but Jessica reported strong usage. Any additional comments or explanations?

ANSWERS:

Jessica Ancker:

I think we were talking about different sorts of informational resources. The ones I described were hyperlinks to a medical encyclopedia that allowed people to click on an unfamiliar medical term. These were used by a large proportion of all patient portal users.

Ruth Masterson Creber:

I agree with Jessica. We were referring to different types of informational links. In our study when we performed audit logs, patients did not spend a lot of time clicking on the Medline hyperlinks (2 percent of clicks), which also took them out of the portal. However, we users requested that we could incorporate hyperlinks with explanations of medical terms, specifically acronyms in our portal.

QUESTION:

I work at OpenNotes, a national initiative to spread the sharing of progress notes. You said you need to explore further before considering widespread adoption. Are you looking at both inpatient and outpatient? What are the barriers/concerns?

ANSWER:

Ruth Masterson Creber:

Our hospital was recently awarded a grant from New York state to support the implementation of OpenNotes. We are interested in doing that both for inpatients and outpatients.

QUESTION:

The notes sharing seems to diminish or replace the face-to-face discussions that should be happening. Is there data that shows an increase or decrease in face-to-face interaction with portal use?

ANSWER:

Ruth Masterson Creber:

I do not know of data in inpatient portals that shows an increase or a decrease in face-to-face interaction. From a qualitative perspective, users reported opportunities to digest what clinicians said through reading the notes, and being more prepared and better equipped for the short one-on-one encounters.

QUESTION:

Did the inpatient portal permit the patient to download the information viewed while they were in the inpatient encounter? What format was used to output that information? Was all portal-accessible information included in the output document?

ANSWER:

Ruth Masterson Creber:

No. The patients had access to the inpatient information while they were inpatient, but they did not download and export that data at discharge. We have not had any patients ask about that functionality, but that is certainly something that we are considering.

QUESTION:

Have you thought about establishing clinics/medical settings as access points for Internet access as a way to create comfort with tech for patients and provide training as well?

ANSWER:

Courtney Lyles:

Yes. I think clinics should be thinking about digital literacy capacity more generally, especially given the number of tools and options we continue to develop and offer to our patients. It would be wonderful to offer computer access and support within the clinics themselves, but linkages to community-based resources on this topic (e.g., public libraries, community centers, etc.) will be critical.

QUESTION:

Why do you think Kaiser has been much more successful than other systems with enrollment and use? In the study presented today, there was still a 60-point gap between those who had the option and those who used the portal.

ANSWER:

Courtney Lyles:

Kaiser has had a long history of portal enrollment, and is therefore several years ahead of many other health care systems on this issue. They also have incorporated portal use into the standard business model for their organization (that is, actively promoting virtual modalities of care at all sites), as opposed to an additional option for patients to access. Finally, Kaiser patients may have higher health and digital literacy capacity overall, leading to greater uptake compared to traditional safety net settings.

QUESTION:

What are the next frontier(s) in patient portal use by the pioneers, such as Kaiser?

ANSWER:

Courtney Lyles:

The next frontiers for portal use in my opinion include integrating patient-reported/tracking data into the EHR, more widespread proactive patient education and support via digital communication, and continuing to understand disparities in use to ensure diverse patients are utilizing the technologies that can improve health outcomes.

QUESTION:

Would you say that switching from an opt-in to an opt-out policy was a big factor in increasing patient portal participation?

ANSWER:

Jessica Ancker:

Yes. Even before the policy change, most people who were offered the portal accepted the offer, and most who accepted the offer ended up using the portal a few times. After the policy change, we saw the same thing—more people were offered the portal, more accepted the offer, and more became repeat users.

QUESTION:

You mentioned that patient use of the portal rose from 20 percent to 32 percent. How did you measure use of the portal? Did you determine that the patient logged in once or more? Or did you consider what type of use they were engaged in? What did they use the portal to do?

ANSWER:

Jessica Ancker:

For that slide, we counted users as people who had logged on twice. So that's a very low bar for use. Overall, we have seen the same types of patterns that other organizations have seen—the most popular functions were viewing laboratory results and messaging the doctor.

QUESTION:

What's your sense of physician satisfaction with responding to questions submitted through patient portals, including doctors without many capitated patients on their panels?

ANSWERS:

Courtney Lyles:

While there is not a large amount of data on the topic of physician satisfaction with portals, these articles might be useful on this topic: https://www.jmir.org/2015/2/e40/ & https://www.jmir.org/2016/1/e8/.

Jessica Ancker:

We have not looked at this question ourselves, but I agree that it's an important one.

QUESTION:

Can you provide any information regarding Web Content Accessibility Guidelines (WCAG)? WCAG 2.0 covers a wide range of recommendations for making Web content more accessible. Following these guidelines will make content accessible to a wider range of people with disabilities: http://www.w3.org/TR/WCAG20.

ANSWERS:

Courtney Lyles:

I agree that these WCAG guidelines are critical for portal accessibility. To date, it is my understanding that the official accessibility/usability of portal Web sites has not been held to these standards among the major EHR vendors.

Jessica Ancker:

I concur!

QUESTION:

Where can I find a compilation of evidence-based best practices for implementing patient portals?

ANSWER:

Courtney Lyles:

This resource from the California Health Care Foundation provides some nice materials for portal implementation: http://www.chcf.org/patient-portals.

QUESTION:

Do you think the adaptation to patient portals will change with upcoming populations, such as when Millennials age and develop medical problems and require both in- and outpatient care?

ANSWER:

Jessica Ancker:

Yes, absolutely. We are already seeing cohort effects as younger patients who are digital natives start aging into older age categories. We also see patients starting to apply their

expectations from the rest of their life to their medical care – people who are accustomed to banking or ordering services online don't understand why they can't expect that same type of service from their healthcare provider.

However, I would like to add a caveat. Poverty and low educational level are both strongly correlated with poor health status. That means that in every age, the people who do *not* use the latest information technologies are also disproportionately the people with the worst medical problems. We constantly need to be thinking about how to improve our outreach to these most disadvantaged patient groups, and cannot simply assume that if we wait long enough, they will jump on the digital bandwagon.

QUESTION:

Do you have suggestions for preventing patient use of messaging through the portal with issues that require more urgent attention?

ANSWERS:

Jessica Ancker:

At our institution, when a patient opens a new message template, a large red message tells them **not** to use the message for urgent matters, and provides a phone number alternative. At other institutions, I've seen a required checkbox that a patient must click to confirm that the message is not urgent. I've also observed doctors reinforcing this point in oral conversations with patients.

Ruth Masterson Creber:

On the inpatient side, we have reinforced this with patients as well. They should not be messaging anything that needs immediate attention.

QUESTION:

Have there been any legal actions on the part of patients/consumers involving failure of providers to respond in a timely fashion to patient-generated communications using the portal? What risks do you foresee?

ANSWER:

Jessica Ancker:

I am not familiar with any actions of this sort.

QUESTION:

Could you address download functionality and prevalence (portals that can download, providers that implement, patients that use)?

ANSWERS:

Courtney Lyles:

This article from the VA about their Blue Button download functionality might be helpful: https://academic.oup.com/jamia/article/21/4/657/2909311/Blue-Button-use-by-patients-to-access-and-share.

Jessica Ancker:

In general, a meaningful use-compliant organization must offer some sort of download functionality. Anecdotally, I have observed the Blue Button standard being used very frequently for this purpose. In a different study, we observed patients as they tried to use the download function, and found that many patients had difficulty figuring out how to use it, or understanding

how it might benefit them. This needs to be made as usable and user-friendly as possible to ensure widespread use.

QUESTION:

Do any of the presenters use electronic patient forms for patients to complete on their portal and send into the EMR? If so, what has your experience been?

ANSWER:

Jessica Ancker:

Weill Cornell recently launched a portal function that lets people self-report medical data, such as blood glucose and blood pressure. We've developed a small but loyal group of users. We are now looking at results to find out how this might (or might not) be helping health care quality and outcomes.

QUESTION:

We have open notes and allow all EHR content (except protected information, mental health, etc.) to flow. Do you know if this is becoming more popular or do most portal still suppress the notes and scanned documents?

ANSWERS:

Courtney Lyles:

Open notes are becoming more widespread, but are not the standard of care currently. There are some recent papers that include data about open notes from larger health care systems like the VA that might be helpful: https://academic.oup.com/jamia/article/21/4/657/2909311/Blue-Button-use-by-patients-to-access-and-share and http://bmjopen.bmj.com/content/6/1/e010034?utm_source=TrendMD&utm_medium=cpc&utm_campaign=BMJOp_TrendMD-1.

Ruth Masterson Creber:

In the inpatient setting, we have piloted giving full access to inpatient notes to patients. The pilot study went well, and patients were receptive to having access to their notes. However, we have not yet turned it on to all inpatients.

Jessica Ancker:

Weill Cornell recently joined the Open Notes initiative, as did New York-Presbyterian.

QUESTION:

In the outpatient setting, would you recommend that the primary care portal include specialty reports to their portal vs. provider-specific portals (e.g., PCP, radiology, hospital, etc.)?

ANSWERS:

Courtney Lyles:

From the patient perspective, I believe integrated portal Web sites with a single log-in are preferable to separate information based on specialty or provider.

Jessica Ancker:

Broadly, I agree. But there might also be exceptions. Some very good outcomes have been observed with very targeted disease-specific portal-based interventions.

QUESTION:

What are the best strategies for a Federally Qualified Health Center (FQHC) to improve patient portal usage/uptake by patients? We have over 35,000 patients with a token and less than 2,000 patients who have actively enrolled. Will a video be the next way to reach these patients?

ANSWERS:

Courtney Lyles:

I would suggest reviewing some of the materials on the California Health Care Foundation Web site (http://www.chcf.org/patient-portals), as well as contacting an organization like the Center for Care Innovations (http://www.careinnovations.org/programs-grants/spreading-innovations), which has been working on portal optimization for FQHCs for several years. Finally, we recently completed a research article on this topic of implementation in safety net settings: https://academic.oup.com/jamia/article/doi/10.1093/jamia/ocx015/3072321/Meaningful-use-in-the-safety-net-a-rapid.

Jessica Ancker:

The opt-in/opt-out policy data I presented was from an FQHC. We saw massive increases in uptake when the policy was changed from opt-in (a patient or doctor had to request an account) to opt-out (an account was created by the front desk or medical assistant as soon as a patient arrived, except for those who refused it).

QUESTION:

With the rollback of broadband privacy today, does this impact patient portal use/security at all for patients? How do we address trust/privacy concerns for patients?

ANSWER:

Jessica Ancker:

I agree that this is a serious concern. I look forward to seeing whether patients interpret this as impacting the security of their medical records.

QUESTION:

Do patients receive "tickler" messages to sign into the secure portal? Or is it up to the patient to proactively sign in from their phone?

ANSWER:

Courtney Lyles:

Most portal Web sites send out email notifications to sign up/register as well as when a specific secure message is sent to the patient. There are different options based on the portal and the health care system for notifying patients via email when a new lab result or other information is available within their medical record.

QUESTION:

Were any of these patient portals initiated as a meaningful use objective?

ANSWERS:

Courtney Lyles:

Many patient portals within safety net settings like the San Francisco Health Network were motivated by the meaningful use incentive program. Please see this additional reference about portal implementation in several community clinic sites that directly discusses the role of meaningful use in their implementation process:

https://academic.oup.com/jamia/article/doi/10.1093/jamia/ocx015/3072321/Meaningful-use-in-the-safety-net-a-rapid.

Jessica Ancker:

The Institute for Family Health portal has been in use since before meaningful use.

QUESTION:

Providers are not always eager to use a patient portal. How do you motivate them to use it?

ANSWER:

Jessica Ancker:

Find ways to use the portal to offload physician work rather than increase work. Automated delivery of normal lab results (with or without an embargo) is a good example, as is refill of routine prescriptions. As for patient-initiated messages, the Institute for Family Health has had very good experiences developing a triage system, so the message goes to a staff team first to handle routine requests (scheduling, etc.), and only a small number get forwarded to the physician.

QUESTION:

One of the disadvantages of patient portals is that patients have multiple ones (I have six). How can we get the information consolidated and reconciled?

ANSWER:

Jessica Ancker:

I have several myself. There are a limited number of vendors in the field that allow patients to collect and consolidate their own electronic records (e.g., Microsoft Health Vault). But these require a fair amount of initiative and a bit of technical understanding to set up. I would love to see better patient-oriented solutions in this space, but I am also worried that this might be a side effect of our fragmented multi-payer health care system that we can't get rid of.